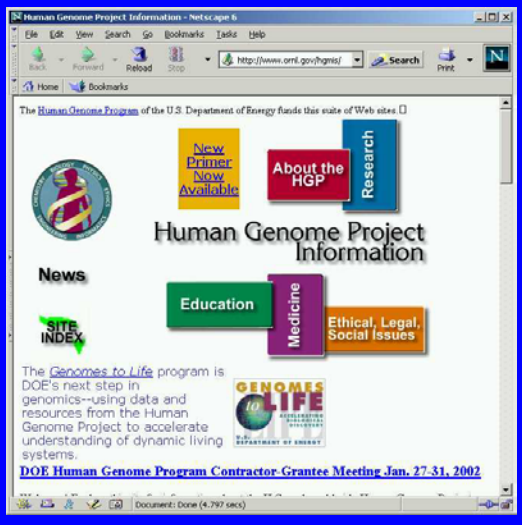
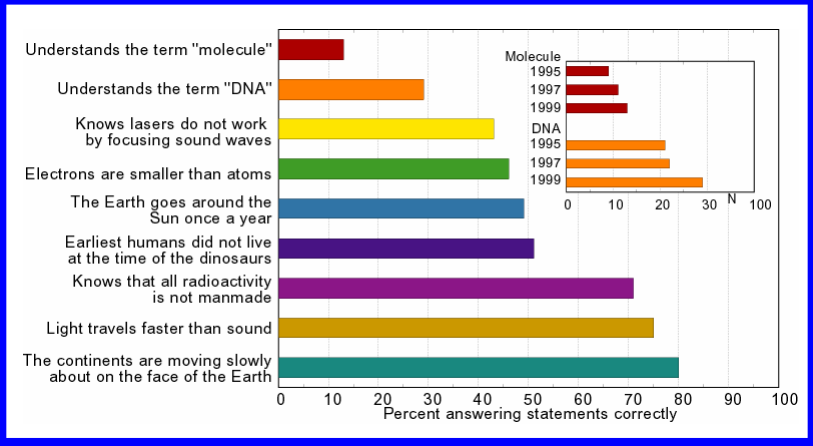
Assessing Models of "Public Understanding" in ELSI Outreach Programs

Bruce V. Lewenstein
Cornell Genomics Initiative
Ethical, Legal, and Social Issues Focus Area

Outreach is important, right?



Public understanding of scientific terms and concepts: 1999



Source: NSB, Science & Engineering Indicators, 2000, ch. 8

CORNELL

But why? Science literacy is...

- Practical science literacy
- Civic science literacy
- Cultural science literacy

- All are forms of "public understanding"
- Driven by belief in value of scientific knowledge and scientific approach to world

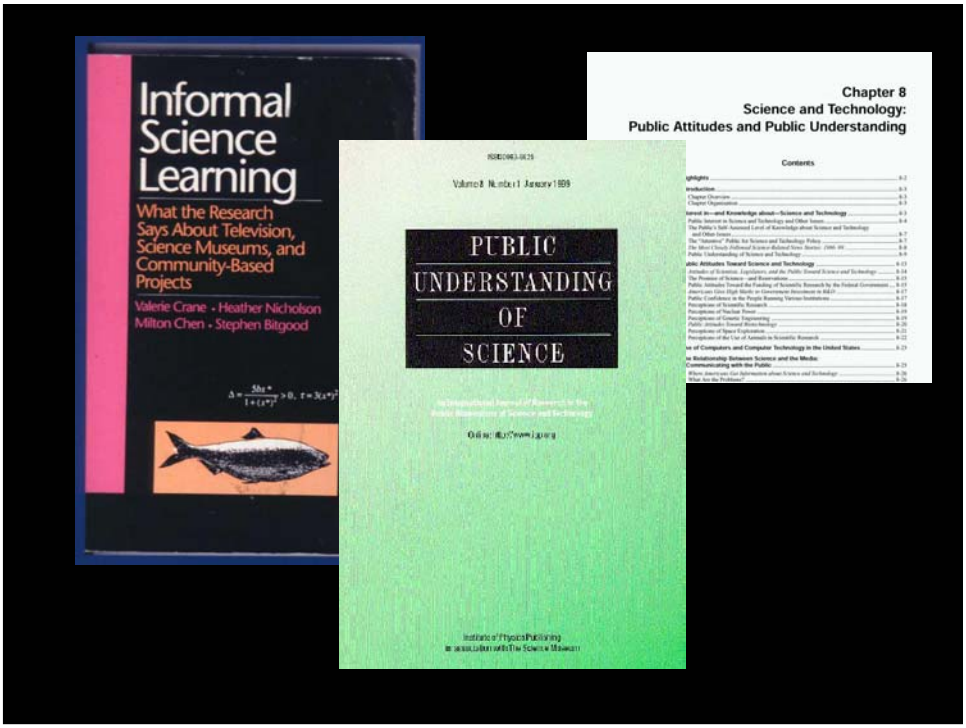
CORNELL

But *evaluation* means hard questions

- Move beyond "we do it because it's important"
- Define goal: What constitutes "success"?
- How do we measure progress to that goal?
  - Move beyond: we'll know it when we see it

Sidebar:
What is evaluation?

CORNELL

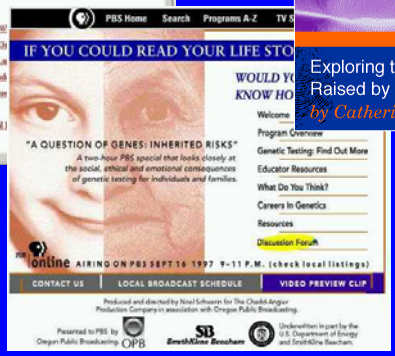


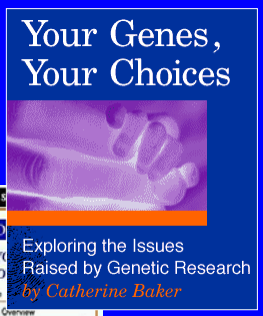
Deficit model

- Longstanding concerns about lack of public knowledge
- More knowledge is better ("fill the deficit")
  - Measures of scientific knowledge
  - Best known: biennial NSF survey of public knowledge and attitudes
- Many excellent educational materials produced

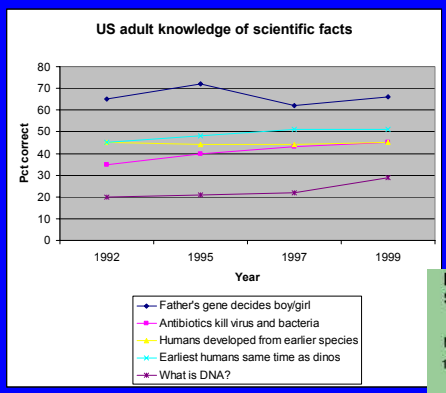
CORNELL

Deficit model



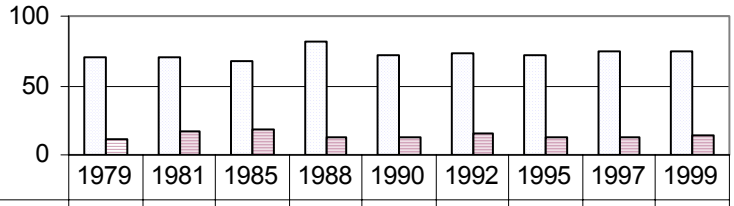


CORNELL



Data: NSF Science & Engineering Indicators, 1992-1999

Public assessments of scientific research



	1979	1981	1985	1988	1990	1992	1995	1997	1999
Benefits outweigh harms	70	70	68	82	72	73	72	75	74
Harm outweighs benefits	11	17	19	13	13	16	13	12	14

Benefits outweigh harms Harm outweighs benefits

Critique of deficit model

- Measures knowledge without context
- Despite 50 years of effort, no apparent change in public knowledge
- No demonstrated link between knowledge and support
- Doesn't address public participation

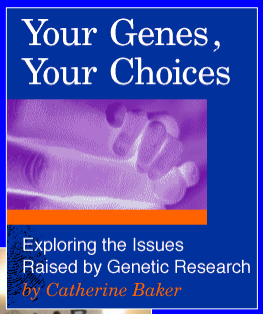
CORNELL

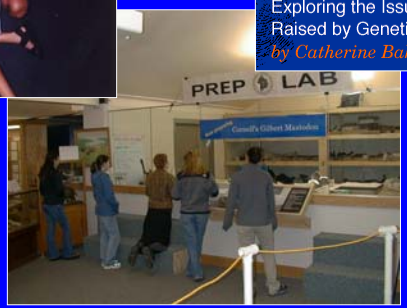
New models

- Contextual model
- Lay knowledge/lay expertise model
- Public participation model

CORNELL

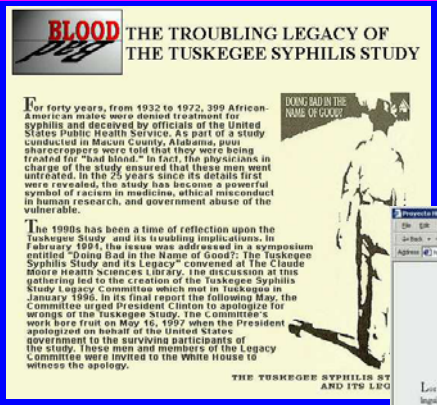
Contextual model





CORNELL

Contextual model


BLOOD

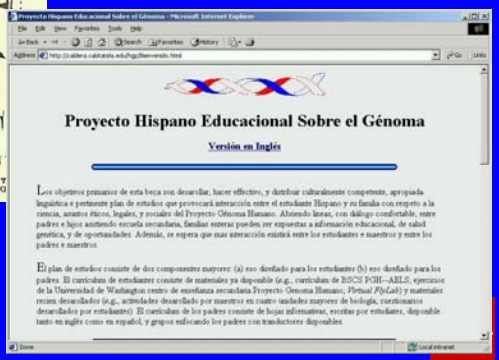
THE TROUBLING LEGACY OF THE TUSKEGEE SYPHILIS STUDY

For forty years, from 1932 to 1972, 399 African-American males were denied treatment for syphilis and deceived by officials of the United States Public Health Service. As part of a study conducted in Macon County, Alabama, poor sharecroppers were told that they were being treated for "bad blood." In fact, the physicians in charge of the study ensured that these men went untreated. In the 25 years since its details first were revealed, the study has become a powerful symbol of racism in medicine, ethical misconduct in human research, and government abuse of the vulnerable.

The 1990s has been a time of reflection upon the Tuskegee Study and its troubling implications. In February 1994, the issue was addressed in a symposium entitled "Doing Bad in the Name of Good?: The Tuskegee Syphilis Study and its Legacy" convened at The Claude Moore Health Sciences Library. The discussion at this gathering led to the creation of the Tuskegee Syphilis Study Legacy Committee which met in Tuskegee in January 1996. In its final report the following May, the Committee urged President Clinton to apologize for wrongs of the Tuskegee Study. The Committee's work bore fruit on May 16, 1997 when the President apologized on behalf of the United States government to the surviving participants of the study. These men and members of the Legacy Committee were invited to the White House to witness the apology.

DOING BAD IN THE NAME OF GOOD?

THE TUSKEGEE SYPHILIS ST
AND ITS LE


Proyecto Hispano Educacional Sobre el Génoma - Microsoft Internet Explorer

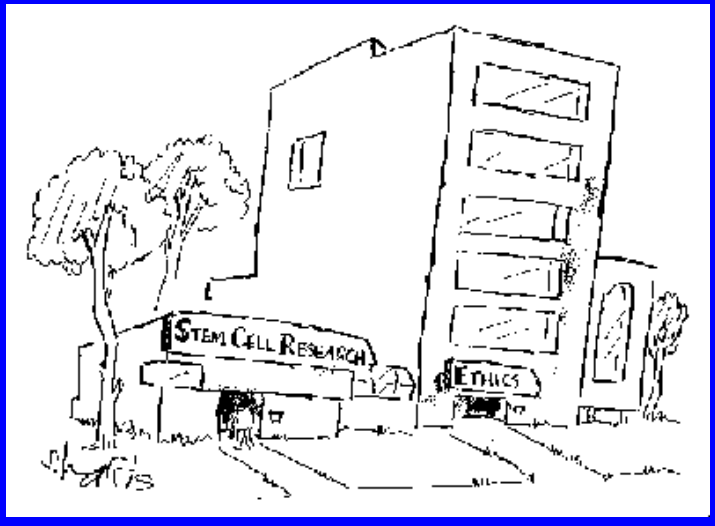
Proyecto Hispano Educacional Sobre el Génoma

Versión en Inglés

Los objetivos primarios de esta beca son desarrollar, hacer efectivo, y distribuir culturalmente competente, apropiada lingüística e pertinente plan de estudios que provocará interacción entre el estudiante Hispano y su familia con respeto a la ciencia, asuntos éticos, legales, y sociales del Proyecto Génoma Humano. Abriendo líneas, con diálogo confortable, entre padres e hijos asistiendo escuela secundaria, familias enteras pueden ver expuestas a información educacional, de salud genética, y de oportunidades. Además, se espera que mas interacción existirá entre los estudiantes e maestros y entre los padres e maestros.

El plan de estudios consiste de dos componentes mayores: (a) uso diseñado para los estudiantes (b) uso diseñado para los padres. El curriculum de estudiantes consiste de materiales ya disponible (e.g., curriculum de BSCS POE--AELS, ejercicios de la Universidad de Washington centro de enseñanza secundaria Proyecto Genoma Humano, Virtual FlyLab) y materiales recien desarrollados (e.g., actividades desarrollado por maestros en cuatro unidades mayores de biología, cuestionarios desarrollados por estudiantes). El curriculum de los padres consiste de hojas informativas, escritas por estudiantes, disponible tanto en inglés como en español, y grupos enfocando los padres con transductores disponibles.

Lay knowledge/expertise

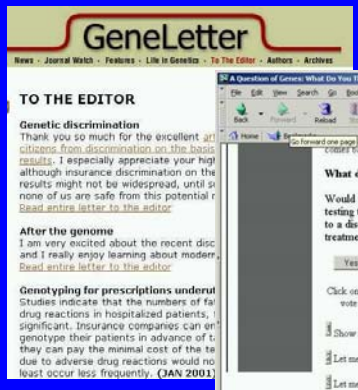


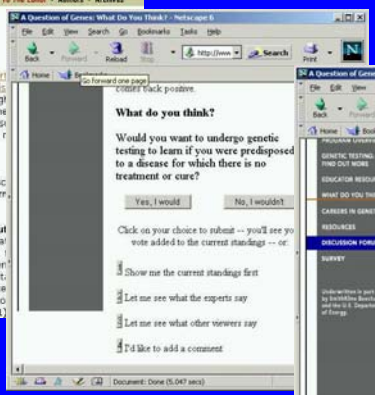
CORNELL

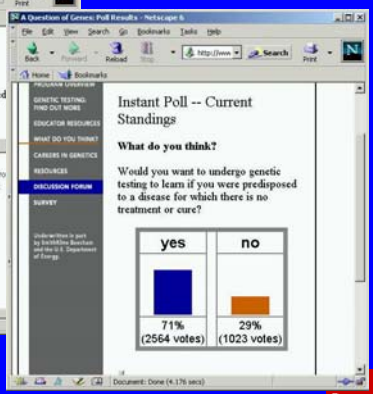
Lay knowledge/expertise

CORNELL

Public participation

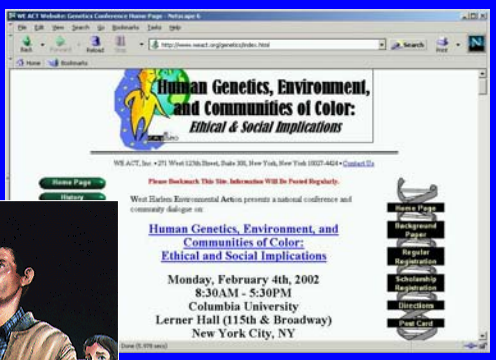


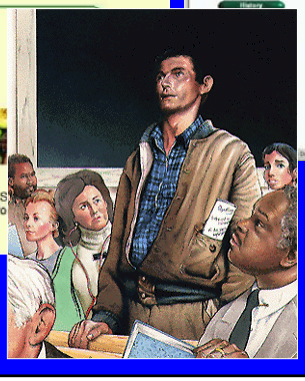




CORNELL

Public participation





CORNELL

Evaluation questions to ask, 1

What are the goals of ELSI outreach?

- Personal efficacy
  - in personal decisions
  - taking part in policy
- Public understanding to create better public appreciation of benefits of science
- Public participation in policy-setting
- Recruitment to science careers
- Trust in scientists, trust in scientific institutions
- Public control of scientific resources, funding, research agenda
- And… or….?

CORNELL

Evaluation questions to ask, 2

- What data do we need?
  - Pre- and post- data
  - Knowledge assessments
  - Attitude measures
  - Behavior (planned or actual)
  - Social/political changes
- What methods of data collection?
  - Both quantitative and qualitative

CORNELL

This project's goal

- To test and refine the models of public understanding of science
- To assess the models at work in ELSI outreach projects
- To suggest ways of using theory-based evaluation to continue strengthening ELSI outreach

CORNELL

Acknowledgements

- Funding: DOE, WHO
- Project staff, formal and informal
  - Dominique Brossard, post-doc
  - Andrew Pleasant, doctoral student
  - Matt Nisbet, doctoral student
  - Adrianne Kroepsch, undergraduate student

CORNELL